

Eliciting End-of-Life Treatment Preferences

I. Theoretical Issues

Simply stated, a preference is composed of:

A. Values

- Values describe what is important in life and what makes life worth living. Self-sufficiency, being free from pain, having "quality" life, and maintaining close friendships are all examples of values. When talking about medical care, values are often described by patients in terms of goals of medical care. Usually goals promote values. For example, keeping the pt comfortable, prolonging life as long as possible, or promoting "quality" of life. Patients' values may also be uncovered when they give reasons for certain treatment wishes or for beliefs about life-sustaining treatment.

B. Outcomes

- When a person makes a choice between several alternatives, they are usually looking at the potential outcomes for each alternative and then weigh them based on their previously held values. In the case of end-of-life treatment decisions, the outcomes for different treatments (e.g., CPR) can be understood in terms of likelihood of return to present state, survival with disability or death.

C. Risk

- Some people are risk takers and some are risk averse, and this characteristic may be independent of how much a person values a given outcome state.

II. Initiating the Discussion

A. Make these discussions routine

B. Choose a good setting

C. Be clear and direct - avoid vague terminology

III. Explore Patient's Values and Goals

A. Explore reasons - ask "why?"

- *Pt: I don't want you to ever put me on one of those breathing machines.*
- *Dr: Can you tell me why you feel that way?*

B. Shared understanding

- *Pt: As long as my quality of life is good, I'd want to go for everything*
- *Dr: How do you define a good quality of life?*

IV. Provide information

A. Discuss likely scenarios

- It is often easiest to ground these discussions in terms of scenarios that patients can understand. Try to learn if the patient has ever experienced end-of-life decision-making with a family member or friend.

B. Discuss risks/probabilities

- Anchor probabilities - Ask how the patient would feel if there was no chance of recovery and if there was 100% chance. Then see how they feel about intermediate probabilities (e.g., would 5% chance be enough, would 10% be enough?)
- Try not to only use only qualitative terms for probability (e.g., "you probably wouldn't do well"). Using numbers ensures that you and the patient are talking about the same thing.
- The framing effect - patients don't interpret a 10% chance of surviving and a 90% chance of dying in the same way. When using numbers, try to frame them in both ways.

C. Outcomes

- Don't just talk about the dire scenarios of persistent vegetative state and terminal illness, or scenarios in which the patient is almost sure to get better. Focus discussion on the "gray zone" of decision-making.

V. Make a recommendation

A. Giving a recommendation respects a patient's autonomy. Just be clear that the patient understands that this is your opinion, not a medical truth.

- *If you were to undergo CPR, on average I would expect someone like you to have a 5% chance of surviving and leaving the hospital. That means that 95 out of 100 people who require CPR don't survive. Given the low probability of success and the risk that you may get resuscitated only to find yourself with severe brain damage, I would recommend against using CPR. However, I would like to hear your feelings on this and will respect whatever you choose.*

VI. Ask patient to choose a surrogate

A. Urge patient to discuss values and preferences with surrogate

- Research shows that without these discussions, surrogates cannot predict patient preferences any better than chance.

B. Ask patient how much leeway they want the surrogate to have when interpreting their advance directive.

- Patients' feelings on this question vary significantly: Approximately 1/3 of patients would like their surrogate to have complete leeway when making decisions about life sustaining treatments, while 1/3 would want their advance directive followed explicitly.

VII. Reassure patient about supportive care

A. Too often, patients view these discussions as focusing on what we won't do for them. Tell patients what we will do for them.

VIII. Invite future discussions